Enhancing and Accelerating the Pace of Autism Research and Treatment

The Promise of Developing Innovative Technology

Matthew S. Goodwin
The Groden Center, Inc., Providence, Rhode Island

Keywords: autism; innovative technology

In a previous In FOCUS column, Kimball and Smith (2007) nicely articulated the benefits and challenges of creating computer technology to support individuals with autism. They also provided a well-devised three-point plan to stimulate and support progress in technology development for this population. As a follow-up to their column, the current offering expands the discussion by (a) highlighting additional technologies emerging in the field (and as available, providing sample citations or URLs to exemplify each technology), (b) detailing the many ways these innovative technologies can be used to enhance and accelerate the pace of autism research and treatment, and (c) describing the Autism Speaks–Innovative Technology for Autism (ITA) Initiative as a resource to complement and aid Kimball and Smith’s call for further technology development.

Although Kimball and Smith (2007) mentioned computer software for persons with autism, there are several additional innovative technologies being developed for this population that utilize the Internet; audio and video recorders; electronic sensing technology; computer architecture, hardware, and software; virtual reality; and robotics. These technologies, alone or in conjunction, can be used beneficially in a number of critical areas affecting individuals with autism, their families, and the professionals who support them.

Benefits of Developing Innovative Technologies for Autism

Access to Resources

There are various challenges in delivering health care to families with autism. For example, access to professionals experienced with autism is limited and families may wait for weeks or months for an appointment. Even if they are fortunate enough to get appointments immediately, families far from major medical centers must often travel great distances to gain access to the relatively few autism experts. Telecommunication technology that utilizes the Internet can support long-distance clinical health care, patient and professional health-related education, public health, and health administration. For instance, a secure online environment has been developed for families with autism to archive personal health and education information and allow authorized professionals anywhere in the world to access it (e.g., Personal Health Record; https://www.caringtechnologies.com/mchr///?sddid=WJicvD44mBdk3ZFvKTEWvz7uIrwGZpwqU&md=1).

Assessment Efforts

Families often struggle to convey to neurologists, psychologists, and psychiatrists clinically relevant behaviors needed to make accurate assessments. Also, it is often difficult to accurately sample prototypical behavior during an office visit because individuals with autism may not demonstrate the target behavior or may find it difficult to adapt to the clinical environment, preventing a useful examination. Telecommunication systems could...
improve a provider’s understanding of an individual’s behavior and subsequent treatment plan if a caregiver had the resources available to videotape an episode of concern where and when it happened and transfer the video to the appropriate health professional via the Internet. Upon receipt, health professionals could review the video, archive the episode for future reference and research, and respond to the caregiver by phone, letter, or e-mail. Audio and video technologies are being developed that enable caregivers to record, annotate, and communicate behavioral data via the Internet from classroom, home, and clinical settings (e.g., BI Capture; http://www.caringtechnologies.com/bicapture). Information technologies are also being developed to facilitate screening and diagnosis in geographically distributed populations by administering standardized neuropsychological and behavioral tests in schools, homes, and other nonclinic and nonhospital locations. These computer-based assessments can transfer data to a centralized location via the Internet for algorithmic analysis, clinical interpretation, and feedback (e.g., The Autism Collaborative; http://www.AutismCollaborative.org/).

Promote Interventions

According to a recent review of publication trends in autism, assessment research has been found to be the most represented and funded (de la Cruz et al., 2006). A great majority of this research focuses on epidemiology, genetics, and neuroscience. Although all of these investigations provide critical data for understanding the cause and course of the disorder, very little of this information translates into practice for individuals who currently have a diagnosis. There is clearly a need for more intervention research that can help individuals with autism, their caregivers, and educators. Emerging technologies carry great potential for providing innovative, individualized interventions. For instance, many people with autism are highly interested and motivated by computers, and computer-assisted learning can focus on numerous academic and support areas of need such as emotion recognition, social interaction, and communication.

Computerized educational products include DVD-based programs that help individuals with autism look at the human face and learn about emotions (e.g., Transporters; http://autismresearchcenter.com/books/dvdvideo.asp). Another computer-based system uses interactive virtual peers (VPs)—3-D, life-sized, computer-animated characters that look like children and communicate with speech and gestures—to explore social interactions (e.g., http://articulab.northwestern.edu/projects/samautism/). Although VPs are not meant to replace interactions with real peers, they may provide a scaffold for developing skills necessary for successful real-world interactions. Interactive computer simulation software developed to teach novice tutors (e.g., educators, parents, siblings) discrete trial training techniques (e.g., DTkid; Randell, Hall, Bizo, & Remington, 2007) is also underway. Finally, sociable robots and dolls able to track faces, expressions, and eye gaze are being developed to teach individuals with autism communication and social interaction skills (e.g., turn taking, imitation) in a way that is more engaging and less stressful than face-to-face human interaction (e.g., The AuRoRA Project; http://homepages.feis.herts.ac.uk/~comqbr/aurora/index.html).

Skill Generalizability

Although there has been an explosion of structured learning programs for individuals with autism, many of the skills acquired during such trainings fail to generalize to novel environments. Sophisticated training packages that are engaging and easy to administer could promote learning across contexts. For instance, virtual reality (VR) technology may provide a relatively low-cost way for individuals with autism to practice rule learning and repetition of tasks across contexts. VR technologies are being adapted to teach individuals with autism a variety of skills (e.g., making choices, conflict resolution, road safety) that may generalize to their everyday lives (e.g., d02Learn; http://www.dotolearn.com/aboutus/research.htm). The aim of VR is not to circumvent real-world social interaction altogether but to provide a teaching aid that allows practice and demonstration alongside normal input from teacher or support workers.

Reducing the Cost of Treatment

Based on recent statistics from the U.S. Department of Education and other governmental agencies, the Autism Society of America (ASA) estimates that the prevalence of autism spectrum disorder could reach 4 million Americans in the next decade (ASA, 2008). The total annual societal per capita cost (including both direct and indirect expenses) of caring for and treating a person with autism in the United States is estimated to be $3.2 million and about $35 billion for an entire birth cohort of people with autism (Ganz, 2007). The rising prevalence of autism, exorbitant cost of treatment (e.g., behavior therapy alone can cost upwards of $60,000 per year), and relatively limited professional resources available suggest that innovative technologies should be explored to reduce some of these expenses. Providing portable and in-home
computerized educational and self-management tools may transfer skills to caregivers and persons with autism and reduce reliance on costly professional consultation.

Portable, wearable sensors are being used to record autonomic nervous system functioning in persons with autism to help them understand, communicate, and regulate their arousal levels (e.g., Goodwin et al., 2006). Also under development are systems that utilize wearable cameras and pattern recognition software to infer socioemotional states using nonverbal cues such as head and facial displays of people and communicate these inferences to the wearer via visual, auditory, and tactile feedback (e.g., http://www.pbs.org/kcet/wiredscience/video/100-face_reader_ep_101.html). Computerized, mobile tools such as personal digital assistants (PDAs) are also coming to market to help individuals with autism organize their materials, establish schedules, and provide cues for completing day-to-day tasks (e.g., Symtrend; http://www.symtrend.com/tw/public/tours/autism.html). Finally, speech technologies, which include speech recognition, speaker recognition, speech synthesis, and voice transformation (e.g., Center for Spoken Language Understanding; http://www.cslu.ogi.edu/projects/researchprojects.html), are making tremendous advances in terms of accuracy, quality, and user adaptability and can be used for a wide range of assistive, diagnostic, and remedial purposes.

Research Recruitment and Implementation

Research recruitment involves matching parents of individuals with autism with local and national institutional review board–approved research studies for which they are uniquely qualified. Each year, many autism studies are not completed because scientists cannot find enough qualified participants in a timely manner. Information systems technologies that utilize easy-to-use, secure, Web-based platforms can support data collection and transmission, information retrieval, and communication. An example of an information system technology for autism is the newly founded Interactive Autism Network (IAN; http://www.IANproject.org). IAN promotes data collection and research recruitment by enabling parents of individuals with autism to participate in research studies by sharing valuable genealogical, environmental, and treatment data from remote locations (e.g., home or office) using the Internet.

Barriers to Realizing the Promise of Innovative Technologies

As Kimball and Smith (2007) aptly indicated, the primary barrier to creating and utilizing emerging technology in autism research is funding exploratory/development research. A key and effort-wise, nontrivial technology development step is needed to generate pilot data necessary to obtain more substantial funding for projects with important relevance to autism research and treatment. Autism Speaks–Innovative Technology for Autism (ITA) Initiative is perhaps the closest currently available mechanism to begin addressing this funding gap. Originally started by Cure Autism Now, ITA was designed to support collaborative efforts between technology developers, social scientists, and neuroscientists to create technologies that either help manage the everyday challenges faced by those with autism, support development and education, or assist researchers studying the fundamentals of autism biology and treatment. The ITA workgroup and its resources also serve to disseminate research and to actively recruit new investigators to the field by providing midsized multiyear grants, fast-track bridge grants, educational programs, and a workgroup within which investigators can meet, share information, and collaborate to create further advances in scientific knowledge regarding autism (http://www.autismspeaks.org/science/research/initiatives/ita_initiative.php).

Conclusion

Innovative technologies carry great promise for enhancing and accelerating the pace of autism research and treatment. Increased support for this initiative is needed to facilitate collaborative arrangements between technologists and various stakeholders in the autism community. It is hoped that mobilizing available opportunities and resources for technology development will translate into better understanding, support, and treatment of one of the most debilitating neurodevelopmental disorders of humankind.

References


**Matthew S. Goodwin**, MA, is the associate director of research at the Groden Center—a school for autism spectrum disorders (ASD) in Providence, RI, serving more than 800 families—and a PhD candidate in the behavioral science program at the University of Rhode Island. He serves on the editorial board for *Focus on Autism and Other Developmental Disabilities* and is the academic and industry liaison for Autism Speaks–Innovative Technology for Autism Initiative. He has more than a decade of research and clinical experience working with the full spectrum of children and adults with ASD and has extensive experience using innovative technologies for behavioral assessment, including telemetric physiological monitors, accelerometry sensors, and digital video/editing systems. Please address correspondence to Matthew S. Goodwin, 86 Mt. Hope Ave., Providence, RI 02906; e-mail: msgoodwin@earthlink.net.